

STATEMENT ON S.2053

The Community and Family Living Amendments of 1983

of

K. Charlie Lakin, Ph.D.
Center for Residential and Community Services
Department of Educational Psychology
University of Minnesota
218 Pattee Hall
150 Pillsbury Drive, SE
Minneapolis, MN 55455

Before the

Senate Finance Committee
Subcommittee on Health
Minneapolis, MN

August 13, 1984

STATEMENT OF K. CHARLIE LAKIN, Ph. D. on S.2053
The Community and Family Living Amendments of 1983

I am Charlie Lakin, Senior Scientist at the Center for Residential and Community Services at the University of Minnesota. Our Center was initially funded in 1976; since that time we have studied the deinstitutionalization process and the development of community services for developmentally disabled people throughout the United States.

In 1977 we gathered data from more than 6,000 residential facilities, including state institutions, group homes, and specialized foster homes. In 1979 we sent interviewers to 75 institutions and 161 community facilities across nation. Interviewers gathered detailed information regarding more than 2,000 mentally retarded residents, their abilities and disabilities, the services they needed and the services they received, their family, social and leisure activities. Two years ago (1982), we surveyed 14,605 private licensed and 1,028 public residential facilities in the United States. We have completed numerous other studies.

The residential care system has been profoundly influenced by the federal Medicaid program since 1971, when Congress authorized Medicaid funding for care for mentally retarded people in public institutions. In authorizing ICF-MR reimbursement, two clear purposes were evident: first, to help states cover steadily increasing costs of institutional care; second, to guarantee minimally adequate habilitative programs. ICF-MR regulations were published in 1974.

Today all but two states (Arizona and Wyoming) participate in the ICF-MR program; 58.7% of all 243,700 mentally retarded people in licensed mental retardation facilities in 1982 were in ICF-MRs. The number of ICF-MR residents grew from 108,000 in 1977 to 143,000 in 1982, while the average size of ICF-MRs decreased from 188 to 77 beds. ICF-MR facilities with 15 or fewer

residents increased in number from 188 in 1977 to 1,202 in 1982, but still housed only 6.8 percent of all ICF-MR residents.

One of the most important questions raised by the growth of the ICF-MR program has to do with the appropriateness of the level of care it provides. The target population for which ICF-MRs were originally intended can be viewed as the 166,000 residents of state institutions in the early 1970s. Despite its recent growth, the ICF-MR program has not expanded beyond the size of its originally envisioned target population, with only 143,150 beneficiaries on June 30, 1982. Far from utilizing intermediate levels of care for persons who were less impaired than the original target population, there has been a general trend toward a more severely/profoundly retarded population than in the 1974 state institutions. And while the use of intermediate levels of care has varied considerably from state to state, only eight states increased the proportion of mild/moderately retarded persons in their 1982 ICF-MR programs to more than five percent above the proportion in state institutions in 1974. Not surprisingly, this group contained seven of the nine states that have private ICF-MR industries providing more than 35% of their ICF-MR beds.

The increasing costs of the ICF-MR program are attributable both to growth in the number of recipients and increases in the cost per beneficiary. However, since 1977, 70% of the increase in total program costs have been attributable to increases in per resident costs. The per resident per day cost of the ICF-MR program between June 30, 1977 and June 30, 1982 rose from \$41.96 to \$79.53, or 89.5%. This was roughly comparable to the 81.6% increase in the per day cost of an acute care hospital room over the same period.

While the observation that ICF-MR facilities are more costly than non-ICF-MR certified facilities is easily substantiated, it is also relatively easy to identify factors that are coinvolved with certification that are also

related with cost differences among facilities. Nevertheless, our regression analyses show that Medicaid certification alone accounts for 15% of the variance in residential services costs after controlling all resident, program, and state variables.

Concerns have been expressed that the ICF-MR program, because of the federal money it provides, has created incentives for states to retain institutional models of caring for disabled people at a time when contemporary standards of adequate care emphasize the benefits of smaller community based settings. These concerns derive from the fact that most large state institutions are ICF-MR funded (with the federal government reimbursing 50%-77% of the cost of care) while most small, community-based facilities rely on a Supplemental Security Income, state, and local funds. Our data show that twenty five percent of the variation in the proportion of each state's use of large facilities (16 or more beds) is related to the proportion of their beds that are Medicaid certified. Similarly, states with larger proportions of ICF-MR beds were less likely to have shifted toward the use of smaller facilities between 1977 and 1982 ($r=-.47$).

Straightline projection of past trends to estimate future ICF-MR utilization will probably be inaccurate because of the likely effects of actual and proposed changes in Medicaid policy. The Medicaid waiver authority has offered states a financially attractive alternative to creating small community-based ICF-MRs for persons presently residing in large ICF-MRs. It is significantly affecting the rate at which ICF-MR facilities are being created in community settings. Nevertheless, our review of the first 26 approved state waiver applications indicates that the Medicaid waiver has not dramatically increased rates of deinstitutionalization from state institutions. Because non-Medicaid alternatives are generally considerably less costly than Medicaid certified programs, states appear ready to utilize the

waiver option in pursuit of their past deinstitutionalization goals. However, this new Medicaid option is unique in a very important way; it specifically limits states in total budget and numbers of beneficiaries. States' abilities to benefit from the waiver authority, at least in the short term, are largely predetermined by the nature and extent of their prior ICF-MR participation.

Medicaid legislation and regulations have been developed in reaction to the predominant concerns and evolving standards of adequacy in long-term care systems, first through regulations to improve institutional care, then to permit small facility care, and most recently through the waiver option. As this has happened, the program itself has become much more complex and substantially more variant from state to state. Today state fiscal policy more than client level of care needs or other eligibility standards determine the beneficiaries of Medicaid programs for developmentally disabled people. What is more, as increasing flexibility is offered to states in utilizing their existing Medicaid budget through the Medicaid waiver authority, a condition of relative Medicaid wealth and poverty among states has become more evident. Indeed as Medicaid programs for mentally retarded people have evolved to the point of offering states the opportunity to utilize Medicaid funding for a full continuum of care, states find themselves, because of past decisions with regard to certifying programs for Medicaid, to range from having 90% or more of state long-term care beneficiaries under Medicaid (Minnesota and Rhode Island) to having none (Arizona and Wyoming). Ironically, in many instances states that have relatively small Medicaid budgets have been have leaders in developing community care options. These states in keeping with the prevailing treatment philosophies of the past decade moved large numbers of persons out of ICF-MR facilities into state supported facilities prior to the waiver option. States that have lagged now

find substantial Medicaid funding available for a process that other states undertook without such support. In the future it will be interesting to follow state efforts to increase the number of beneficiaries eligible for waived services. However, rather than simply monitoring the creativity demonstrated by states in maximizing Medicaid contributions to community-based services, it might be more useful to examine ways that a single Medicaid program could be established to realize the flexibility contained in the waiver authority, yet would not deprive states and beneficiaries to program access solely on the grounds of past (and often, at the time, wise) state policy decisions.

If one examines the ICF-MR program historically and legislatively, it seems reasonably clear that the program has essentially accomplished what it was intended to accomplish, that is, to provide fiscal assistance to states to stimulate and assist them in improving quality of care in state institutions. Most observers have noted general improvement in the tolerability of conditions in state institutions since the passage of this legislation and most appear to agree that ICF-MR standards have been a major factor (see Office of Inspector General, 1981). However, since 1971, acceptance of the large, socially isolated residential facility as being capable of providing appropriate care, whatever the conditions of its physical plant and habilitative programming, has decayed substantially. Despite the undeniable trend of preference for and utilization of smaller community-based alternatives for residential care of mentally retarded people, there has been considerable concern that the Medicaid program has done little to influence the delivery of residential services in smaller, more socially integrated models of care, despite increasing evidence of superior habilitative outcomes for residents of such settings. While ICF-MR expenditures for smaller facility care grew manyfold between 1977 and 1982, still less than 6% of ICF-

MR benefits went to beneficiaries in residences of placements with 15 or fewer residents. It is the perceived slowness with which the ICF-MR program is being reoriented toward supporting residential services in community-based settings that has promoted considerable interest in the Community and Family Living Amendments of 1983.

The Community and Family Living Amendments of 1983 (S.2053) and proposed modifications would substantially limit the size of facilities that could qualify any or all of their costs of care for Medicaid reimbursement. S.2053 will undoubtedly make states cautious about assumptions of long-term returns on investments in large institutions, public or private. We at the Center for Residential and Community Services are in general support of S.2053. We have found that there are already many small community based facilities that serve the same health care needs, the same problem behaviors, and handicaps of the same severity that institutions do. The problem has been one of limited availability of community residences. Social research can seldom positively "prove" anything, but with regard to facility quality and size, the preponderance of evidence is supportive of small facilities. Large institutions, where indeed the burden of proof lies, have clearly not been demonstrated to be superior.

Some parents are justifiably alarmed about the prospects of change. Nevertheless, research has shown that many parents who initially opposed the deinstitutionalization of their sons or daughters have been more satisfied after having seen the results. Our own research showed that nearly half of all institutionalized residents in 1978 did not have the benefit of parental contact.

The staff of large facilities are understandably uncomfortable about the prospects of S.2053. However, research indicates that 35% of direct care

staff in institutions leave their jobs in a single year for a variety of reasons other than resident movement (turnover is even higher in community facilities). Many states are already developing transitional employment plans for staff of state operated facilities.

We do have some concerns about increased federal costs due to expanded Medicaid caseloads possible under the current language of S.2053. The issue of recipients and services merits study, and resolution in a manner that does not penalize states with little or with previously decreased ICF-MR utilization. The ICF-MR program has developed to its present state in approximately ten years, a process that has been orderly. The trend toward smaller facilities is already underway, albeit slowly. The case management and planning provisions of S.2053 may well improve the overall development of individually appropriate residential and habilitative services for mentally retarded people in the next ten years.